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ABSTRACT

These proceedings report on activities at an annual meeting of directors of projects administered through the Severely Handicapped Branch, Division of Educational Services (DES) of the United States Office of Special Education Programs (OSEP). The proceedings contain presentations by: (1) Judy A. Schrag, who described the scope and intent of the OSEP mission and discussed critical issues facing special education, including changing populations, personnel needs, and outcome data; (2) Nancy Safer, who presented a framework for the DES mission; (3) Robert Davila, who emphasized the need for effective services for those with disabilities, effective personnel preparation, and increased self-determination for individuals with disabilities; and (4) Patty Guard, who reviewed the principal features of the Americans with Disabilities Act and possible congressional response. Summaries are provided of general sessions on the State and Multi-State Deaf-Blind Projects program and on statewide systems change as it relates to state and multi-state deaf-blind projects. Summaries are also provided of topical sessions on integrated education, transition to adult life, communication and assistive devices, research and innovation, validation, utilizations, personnel training, and demonstration projects. (JDD)

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Severely Handicapped Branch

Project Directors' Meeting

The Maritime Institute of Technology and Graduate Studies
Linthicum Heights, Maryland
November 6-9, 1989

U.S. Department of Education
Office of Special Education Programs
Division of Educational Services

Compiled by:
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Introduction

Severely Handicapped Branch
Project Directors' Meeting
November 6-9, 1989

The annual meeting of directors of projects administered through the Severely Handicapped Branch, Division of Educational Services of the Office of Special Education, was held November 6-8, 1989 at the Maritime Institute of Technology and Graduate Studies, Linthicum Heights, Maryland. Special addresses by four key agency officials, three topical discussion sessions, five program priority sessions, and a project poster session, were combined into a highly productive meeting.

The meeting began with an informal working lunch for directors of State and Multi-State Deaf-Blind Projects followed by a general session which included an overview of the FY 1989 State and Multi-State Deaf-Blind Projects competition. The meeting also included updates on the procedures and policies of the National Technical Assistance Projects (TAC and TASH); presentations addressing the identification, screening, and reporting of children and youth with deaf-blindness; and a discussion of service provisions for families of children and youth with deaf-blindness.

Keynote speaker for the opening general session, Dr. Judy A. Schrag, Director, Office of Special Education Programs, described the scope and intent of the OSEP mission statement. She credited personnel from State educational agencies and institutions of higher education with providing substantive input into the statement's design, and described how these agencies are currently coordinating their efforts to better serve children and youth with disabilities. She acknowledged the significant contribution being made by the projects represented at the meeting in serving children and youth with deaf-blindness and other severe handicaps.

Dr. Nancy Safer, Director of the Division of Educational Services, addressed the second general session, with the topic, "Achieving Important Outcomes." She described the Division's planning strategies for meeting OSEP goals and objectives for the children and youth with disabilities, and reviewed the the interrelationships of the various programs within the division. The critical need for coordination and cooperation in the planning and delivery of services within the States was emphasized by Dr. Safer. Five States: Virginia, Colorado, California, Washington, and Vermont, then presented information on how effective services to this low-incidence and multi-disabled population was being achieved through coordination between the State-Wide Systems Changes Projects and State Deaf-Blind Projects.

Dr. Robert R. Davila, the Assistant Secretary, Office of Special Education and Rehabilitative Services (OSERS), was a featured luncheon speaker. He emphasized the need of effective services to children and youth with disabilities, and endorsed an increased advocacy for active participation of persons with disabilities in meaningful roles in society, and self determination, and for personnel preparation as major objectives of OSERS.

Three concurrent topical sessions addressed: "Integrated Education: State of Implementation and Future Directions," featuring nine presenters with Anne Smith as session coordinator; "Transition to Adult Life," with eight project personnel and chaired by Amy Bennett; and "Communication and Assistive Devices: Reaching Age 22 with Something to Say," discussed by eight professionals with Sara Conlon acting as chair. These sessions were designed respectively to promote the continuing discussion and development of innovative educational research and demonstration project procedures, effective transition practices for addressing lifestyle needs and life choices, and communication skills by children with deaf-blindness and other severe handicaps from infant through young adult levels.

The following morning, five concurrent sessions were held which discussed accomplishments and problems encountered in the administration of the published priorities for the Program for Severely Handicapped Children and Services for Deaf-Blind Children and Youth Program. Each of these sessions included presentations by directors of representative research or demonstration projects, a review of state-of-the-art developments in responding to the priorities, and a discussion of future challenges and possible strategies to effectively address these challenges. The "Research and Innovation" session was chaired by Anne Smith; "Validation," by Sara Conlon; "Utilizations," by Patricia Hawkins; "Personnel Training," by Amy Bennett; and "Demonstration Projects Serving Children and Youth with Deaf-Blindness and Other Severe Handicaps," by Charles Freeman.

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The concluding general session followed the five concurrent priority sessions. At this plenary session, designated spokespersons from the concurrent sessions reported on the principal issues addressed in their sessions, including project findings and accomplishments, current problems being encountered in provision of effective service to children and youth with deaf-blindness and other severe handicaps, and recommendations for possible solutions. The recommendations proposed a variety of programmatic and fiscal actions at local, state and federal levels to more effectively and efficiently meet the identified problems.

Patricia J. Guard, Senior Legislative Analyst of the U.S. Office of Education spoke following the Wednesday noon lunch break. She reviewed the principal features of the Americans with Disabilities Act, and described possible congressional response to this legislation. She then presented a definitive analysis of both House and Senate versions of proposed amendments to the Education of the Handicapped Act, including the apparent intent of such amendments, the effect of various interest groups in support of the desired changes, and a consideration of the likelihood for adoption of the amendments.

Individual and small group discussions were held following the concluding general session for project directors with their respective project officers of the Severely Handicapped Branch. These discussions included a review of current project activities, problems being addressed, and considerations for next steps in effectively administering projects for the maximum benefit to children and youth with deaf-blindness and other severe handicaps.

There appeared to be a general consensus of opinion of project directors and branch staff, that the November 1989 Annual Project Directors' Meeting was very successful. Principal components contributing to this positive assessment were the motivating, informative and timely addresses delivered by Robert R. Davila, Judy A. Schrag, Nancy Safer, and Patricia J. Guard; the stimulating presentations by selected project personnel; the comfortable and exceptionally well equipped facility; and the careful attention given to planning and execution of the meeting's multiple details by the Severely Handicapped Branch staff.

SESSION: General Session No. 1: *State and Multi-State Deaf-Blind Projects Program*

PRESENTERS/TOPICS:

PRESENTATIONS:

R. Paul Thompson, Charles Freeman, Sara Conlon,
OSEP Services for Deaf-Blind Children and Youth

PANELS:

Karen Goehl, Indiana State University
Noah Calloway, Oklahoma SEA
Victor Baldwin, Teaching Research
Identifying, Screening, and Reporting—Children and Youth with Deaf-Blindness
Linda Van Eck, Missouri SEA
Terry Rafalowski, Washington SEA
Providing Services to Families

PRESENTATIONS:

H. D. Bud Fredericks, TASH
Technical Assistance to State and Multi-State Deaf-Blind Projects
Terry Carr, Jane Everson, TAC
Technical Assistance to Facilitate Transition of Deaf-Blind Youth

SESSION CONTENT:

This session included an overview of the FY 1989 State and Multi-State Deaf-Blind Projects competition; a presentation on the Perkins School for the Blind's grant from the Hilton Foundation; discussion of procedures for identifying, screening, and reporting of children and youth with deaf-blindness; providing services to families; and a review of services provided by the technical assistance grantees: TASH and TAC.

1) **Perkins School for the Blind: Grant from the Hilton Foundation**

The Perkins School for the Blind recently received a grant from the Conrad N. Hilton Foundation, of $15 million over the next five years. The purpose of this project is to support development of new programs designed to support multi-handicapped, blind individuals and their families in the United States and countries around the world. The project will have two major components:

INTERNATIONAL PROGRAM: ($1.3 million annually)

- Leadership training for program managers and supervisors;
- Establish regional offices in Asia, Africa, and Latin America, particularly to provide support for developing countries;
- Development of curriculum, instructional materials, A-V products, and dissemination materials, in native languages;
- Offer 15-20 teacher training courses per year in developing countries throughout the world;

NATIONAL PROGRAM:

- Infants and Pre-school age children: Early intervention and consultation to underserved populations in four service areas around the country;
- Parent support and training to assist families to care for and advocate on behalf of their children;
- Development of curriculum, materials, A-V products, research and dissemination materials;
- Teacher training, preservice and inservice, on a national level.

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The grant is intended to support and supplement, not supplant current programs and services for multi-handicapped, blind individuals and their families. Perkins' staff plan to work with programs and personnel already involved in providing the services.

2) **Identifying, Screening, and Reporting Children and Youth with Deaf-Blindness**

ISSUES IN ACCURATE DEAF-BLIND CHILD-COUNT REPORTING:

- Overall, the accuracy of the identification of children and youth with dual sensory impairment has improved, and data submitted by Coordinators of Services for Deaf-Blind Children and Youth indicate that more children are being identified and served.
- The number of children in the birth to three years age group has increased substantially; this may be the result of the Part H EHA initiative.
- Continuing concerns: A large number of children and youth whose etiology is reported as "Other known cause."

EXAMPLES OF STATE REPORTING:

(1) One state, which reported an unusually low number of children and youth, used the following strategies to locate and identify children and youth with deaf-blindness:
- Develop close working relationship with the state department of special education and make the child count an integral part of the survey of all special education children;
- Have a working definition, if not a category, that assists in the identification of children and youth with dual sensory impairment;
- Conduct an aggressive outreach and awareness program with all the programs, including LEAs and state schools, which might be serving the children.

(2) One state, which reported an unusually high number of children used the following strategies to rectify the count:
- Developed a computerized system for better tracking of children with deaf-blindness;
- Went to the institution from which most of the children on the report had been referred, and looked at the records; found that many of the children had been identified as infants; at which time they had met the criteria, but there had been little or no follow-up;
- Followed up with children to determine if they still met the requirement of dual-sensory impairment, found that a number of children and youth should no longer be reported;
- Developed guidelines for identification of children and youth with deaf-blindness, and a computerized system for tracking the children are crucial to maintaining an accurate report of children and youth with deaf-blindness.

3) **Projects Providing Services to Families**

RESPITE CARE PROGRAM

Premises:

- Families with a child with severe disabilities are at risk of dysfunction;
- Support for the family through the extended family alleviates some of the stress and assists the family to keep the disabled child at home;
- The more the male figure in the home is involved in running the home and caring for the child, the greater the chance of the family remaining intact;
- The more that parents are expected to take initiative, become involved and assertive in arranging services for their own child and the family, the greater the chance of success.

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The Model:

- Families can receive up to 21 days of respite care over the year;
- Families are encouraged to find own respite care provider, e.g., extended family member, classroom aide, etc., in order to increase the trust and confidence level;
- Training is provided to families to assist them in recruiting respite care provider;
- Training is provided for the care provider, often in the home with the family;
- Respite care providers are evaluated and must meet acceptable standards to remain on the list of respite care providers.

Outcomes:

- There is less stress on the families and greater chance that they will be able to keep their child with disabilities at home.

Challenge:

- How to help families prepare for the transition of the child into adult life in the community.

FAMILY WEEK-END RETREAT

The Model:

- A week-end retreat at a rustic camp ground is held for families of children who are on the deaf-blind registry;
- Parallel programs are held for the parents and for the children, including the child with disabilities and siblings;
- There is a "featured" speaker, who generally stays for the full time to interact with the families;
- There is also time for parents to interact with each other on an informal basis, to share, learn from each other, and strengthen their support network;
- The "staff" includes the paid staff as well as volunteers, e.g., students from a community college.

Benefits:

- The informal environment provides a real "leveler" effect, allowing parents and staff to get to know each other better, and as individuals;
- The environment facilitates parents developing relationships among themselves;
- The volunteers frequently develop relationships with the child, the siblings, and the parents and often stay involved, sometimes as respite care providers;
- The week-end also serves as a time for parents and families to plan for future activities back home.

To Achieve These Benefits:

- Develop teams to support implementation of the projects;
- Involve all parties in the process, including parents and families; identify and clarify roles;
- Develop linkages on the local level among all key agencies and personnel;
- Use Advisory Committees to facilitate linkages and collaboration;
- Establish and maintain communication among all parties;
- Market the project; inform all involved or potential sites, but also increase general public awareness and understanding;
- Share information on project processes, outcomes, products.

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4) **Challenges and Issues:**

- How to evaluate projects; identify critical issues and assist impact of the projects in effecting change;
- How to balance the different visions and goals of participating parties to formulate a shared vision;
- How to assure long term change that will remain after the projects are completed;
- How to improve understanding of personnel, organizational, and systems change;
- How to develop effective linkages with other relevant agencies, especially those relevant to transition;
- How to maintain the autonomy of the project, within the larger context of the state, in order to maintain flexibility, spontaneity, etc.
- How to adhere to the purpose and plans of the projects, and yet remain open to new ideas and opportunities for program improvement and modification;
- How to take a broad view of implementing best practices in order to achieve sustained change.

SESSION: General Session No. 2:

Presentation:
Dr. Judy A. Schrag, Director
Office of Special Education Programs

How pleased I am to be here with you tonight! I want to share with you some of my thoughts on the challenges facing us as special educators, to talk to you specifically about OSEP's mission, to highlight some of the critical issues facing states, and to relate these issues to the work many of you are doing within your projects.

During the last three years, Dr. Tom Bellamy, my predecessor, corresponded with many people across the country asking for input regarding OSEP's mission. We are now using the outcomes of that effort, presented in draft form in March of 1989, as a basis for further strategic planning at OSEP, and as a basis for refining the principles or expectations that will guide our work at OSEP over the coming years. The following are what we believe to be OSEP's guiding principles:

1. Persons with disabilities must have equality of opportunity, equal access to all aspects of society, and equal rights under the constitution.

2. Persons with disabilities must be empowered to achieve self-sufficiency, independence, and productivity, and to have access to work opportunities.

3. Persons with disabilities must be integrated into the normal working, living, and service patterns of community life.

4. Persons with disabilities should live with dignity, and experience the security of income supplements and medical care as other citizens do and have opportunities for services outside institutional settings.

Within these guiding principles, we believe that the Congress, in creating the Department of Education and the OSEP within OSERS, gave us four tenets. These tenets are known to us all. They are as follows:

1. Children and youth with disabilities should have full and equitable access to education. We believe that Congress asked us to administer a federal law for implementation in the states to assure that no child will be discriminated against; that no child will not have access because the services are not there—it is not a resource issue; and that children will not be excluded arbitrarily.

2. Children and youth with disabilities should receive individualized services. We believe that the strengths and weaknesses of all children, the curriculum decisions, and the instructional strategies should be based on the Individualized Education Plan (IEP). Furthermore, within the IEP, there should be a continuum of services available for all students.

3. Children and youth with disabilities should be integrated into the educational mainstream to the extent possible and have the opportunity to interact with their non-handicapped peers.

4. Parents should be equal partners in the educational process. It should be noted that Part H goes further than Part B; it goes beyond the procedural safeguards when it states that the role of parents are not only central to the delivery of services, but as we plan services for infants and toddlers we must take into account the strengths and weaknesses of the family.

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Within these guiding principles, and the major features of the Education of the Handicapped Act, we have established four goals. Each of you has been given a handout which everyone must understand is only a draft document, meant only to reflect some of the activities at OSEP to which your projects relate. The goals are important to the work you are doing and are organized to reference outcomes that we hope all our formula grants will reflect. The four major goals are:

Goal 1: To increase the effectiveness of educational services for students with disabilities.

Goal 2: To increase the extent and quality of interactions between students with disabilities and their peers who are not disabled.

Goal 3: To promote collaboration on behalf of students with disabilities.

Goal 4: To enhance the capacity of the field of education to provide needed services and meet the requirements in the formula grant sections of the statute.

As we carry out these goals, there are several critical issues facing us in special education.

I. Changing Populations. There are simply more children with learning problems today than ever before. Some school problems are due to handicapping conditions, others are the result of heath conditions, and some are caused by social factors. There are many dimensions of this changing population. In some of the areas, our statistics are inadequate. The following remarks will address several dimensions of our changing population.

Drug Dependent Children. One component of our changing populations is the growing number of drug dependent babies. Some of these babies are likely to have a variety of difficulties including deaf-blindness and severe handicaps. While this is one of the areas that we lack adequate data compiled nationwide, a recent survey conducted in 36 major hospitals found that 11% of the live births are infants who are drug dependent and premature. The Select Committee on Children, Youth and Families has heard testimony recently that today we have three to five times more drug exposed babies than just five years ago. Certainly, we have a lot to learn about this population. We lack good epidemological and longitudinal studies. Yet, we do know that some of them are likely to have the same problems we see today in the children in our severely handicapped programs.

Medically Fragile. At a recent conference on medically fragile children, it was reported there is an increase in the number of medically fragile children. This is due in great part to recent medical advances, i.e. children who would not have survived a short while ago, are now surviving.

AIDS and HIV Infected. In a recent conversation, Dr. Vince Hutchins, Deputy Director of the Bureau of Maternal and Child Health, stated that in statistics collected since 1982, 1,500 children have been diagnosed as having AIDS; approximately 1.5 million children have tested positive for the HIV virus. For this data children are defined as persons from birth to 13 years in age. Many of these children are now in our birth to three and preschool programs and in our public school classrooms. This issue offers much for consideration by educators, school administrators and policy makers. Your projects over the years with children who have infectious diseases will be of value to educators working with this population.

Seriously Emotionally Disturbed. Clearly we have growing numbers of younger children who have emotional problems. I recently visited the San Diego Center for Children, a school for children who have emotional problems, and heard some of their statistics on the prevalence of emotional disturbance in younger children. What I saw and heard there has served to reinforce my commitment to this need. If you have been following the Senate and the House reauthorization bills for the EHA discretionary programs, you know that both have proposed a new discretionary program for emotionally disturbed children. Concern was evident among members regarding the linkages between education, health and medical services for these children, and I believe the language Congress is proposing is tremendously insightful into many of the issues you already are exploring in your programs which deal with emotionally disturbed and severely handicapped children.

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In addition, I believe we need to seriously consider the appropriateness of our policies, and the effect on the child and the family, of sending emotionally disturbed children to distant, often out-of-state, programs. This policy in which they are away from their families and communities may not produce the positive effects we desire.

Hereditary Diseases. We will have also many positive changes in the population of the severely handicapped that we are presently serving. Exciting research in gene therapy and gene splicing is being conducted. For example, they have found that the gene affected by Lesh-Nyhan disease, a disease which results in uncontrolled mutilation, can be isolated from the human bone marrow cell. This medical advance has brought about partial correction of that heredity disease. There are many more advances that could be mentioned; however, the point is that change is ongoing and advances are made daily. We must be vigilant and aware of these advances.

II. Personnel. These advances or other positive activities, however, do not lessen the needed number of well trained special educators and related service personnel. The personnel need is another of the embedded issues in the four goals of OSEP discussed earlier. Each state that has presented its supply/demand data has stated a need for more and continuous training, retraining, recruitment, and retention of special education personnel. It is of great concern to all of us that, on the average, 30% of the special education teachers across the nation do not meet state certification standards and are on emergency certification. It concerns me greatly that our special education teachers are leaving the field at double the rate of regular educators; the attrition rate for regular educators is 6% and for special education teachers it is 12%. Thus, your projects dealing with inservice training, enhancing preservice training capability, working with classroom aides to enhance the skills of existing service providers are vitally important.

III. Outcome Data. Our special education outcome data need to be much better. When you look at the National Longitudinal Transition Study of Special Education Students conducted by the Stanford Research Institute (SRI) International, you find some alarming statistics. For example, out of the 8,000 high school students in the study, one of every three were failing in one or more classes. Within this group 10.5 percent were failing in six or more classes. Of the more than 3,000 youth included in the reported dropout statistics, the dropout rate for students in special education was higher than for their nondisabled peers. While the study found that 56% of special education exiters left secondary school by graduating, many dropped out. One in three exiters from the secondary special education system dropped out of school. Those who were emotionally disturbed had the highest percentage of dropouts (36%). Many of you have transition and work study projects; we appreciate your efforts for we must increase the number of children who have the skills for competitive work once they leave high school.

We have just been through, what I will call, the first generation of issues related to supported work employment and transition. These issues cut across medical and health services. I recently attended a meeting of a panel of experts on supportive work employment. There was a lot of discussion regarding the "smart things" we have learned to help disabled children transition to the world of work. The challenge is how to get the things we have learned into practice; how to get what you are finding in your projects and through the system change grants in your states incorporated within the state infrastructure and at the same time begin to focus on the second generation issues.

The second generation issues concern the need to finetune some of our training; to establish effective linkages between special education, rehabilitation and vocational education; and to make those linkages a part of the educational infrastructure.

As an illustration, at the panel of experts meeting on supportive employment, an executive from a major corporation said that his company had a large investment in the training of new workers. Yet, they know that approximately 80% of what the new workers learn is not from the training, but from peers. When you think about how much we have learned, how much you have discovered about peer instruction and peer tutoring in the schools, it is apparent that you have so much knowledge and expertise to offer in this area. This is an example of a second generational issue of how to finetune some of the training we do.

There is much discussion today relative to the set aside funds in the reauthorization of the Vocational Education Act. Congress would like to do away with the 10% set aside and replace it with accountability language that would assume and require that all handicapped children have access to vocational education training in the schools. Studies indicate that our children with disabilities do have access to vocational education. However, I don't think we have figured out

(continues)

how to effectively link special education and vocational education in our schools, let alone how we make vocational rehabilitation and the Developmental Disabilities Early Planning a part of the infrastructure of the schools.

Several of your projects deal with linkages across agencies. As a matter of fact, it is probably a central feature of all of them, because of the complex needs of the deaf-blind and severely handicapped children. We have learned so much about interagency linkages. One example of our efforts across the country is the State Interagency Coordinating Councils for birth-to-three planning. In addition, schools are now employing more social and health service workers than ever before. I think, however, we have much more to learn about linkages of programs and services. For instance, how do we get the rich resources—the talent and expertise—that are often in our state schools for the deaf and blind into our public schools? How do we allow for a much smoother transition across the continuum of options? There are jurisdictional, governance and mindset issues to deal with. How do we look at tomorrow's continuum of services which must cut across programs to assure that we have integration to the fullest extent possible and maximizes the knowledge we have in each of the pieces or components of the continuum?

While you have learned much about interagency linkages through your projects, I think we have linkages for tomorrow that we have not even thought of for today.

Technology. I think we have technology capability that we have not even started to use. For example, optic fibers have significantly increased our capacity to transmit a vast amount of material in seconds, and we are told that this capability will increase five-fold in the next five years. The technology applications you are using with deaf-blind handicapped children are great advances; and in the same way, due to your efforts and their increased use, their capability will improve in a short time.

Education Reform. Another challenge facing us is to figure out how special education can become more a part of, not distinct from, education reform. Many of us in special education believe that we have been excluded from the education reform movements and ultimately the decisions that followed, and continue to follow. I think we have a lot of challenges in this area. You who have birth-to-three, birth-to-six projects, have the challenge of trying to figure out how to "knit" these programs together to enable a smooth transition from one to the other. There are 33 states who have implemented state-funded disadvantaged, HeadStart-like programs as a part of education reform. It is critical that all of these programs including day-care be carefully linked together. We need to monitor the expectations built by parents whose children receive a more comprehensive program from birth-to-three, and then move into programs for three to five year olds, which may not have as comprehensive an array of services as those explicit in the Part H programs.

Each of your governors has come back to the state from the education summit and put himself or herself on the line. Would you have guessed a few years ago that 50 governors would agree to national standards? I find the eight or nine national goal areas they came up with especially interesting, for many are consistent with what we are trying to do in special education. For example: readiness of children—a good learning, a good language start and reduction of dropouts are two of the goals we have worked on for some time.

I think the question of how choice, one of the Secretary's initiatives, relates to those with disabilities is a very important issue. For example, an unanticipated outcome of choice could be to move back to a more segregated environment. If you look at the literature on choice it provides several features to be considered; not a single one of those considerations, however, deals with disabilities. I think it is terribly important that state-by-state we make ourselves part of the considerations so that we don't have unanticipated outcomes that will negatively impact services for children with disabilities.

We must monitor carefully the increased rigor of graduation requirements. Again we need to look at the unanticipated outcomes of reform measures on special education students. For example, some are concerned that increased graduation requirements have forced the dropping of some electives necessary for our children, which have in turn increased the dropout rate among our students. There are many examples of where we need to be vigilant regarding the impact of education reform on our programs and make sure the implications are clear for all children with disabilities. It is important that special education be an active participant in educational reform discussions and initiatives in each state.

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I am going to close with one other challenge, a challenge certainly to the Higher Education and Adult Training for People with Handicaps (HEATH) Clearinghouse, the National Information Center for Children and Youth with Handicaps (NICHCY), TASH, and the Helen Keller Technical Assistance Center. The challenge is also to every one of your projects, for you are finding an abundance of rich information regarding new models, strategies, curriculum, training, augmentative devices, inservice training, service delivery, etc. We must get information about what we know into practice. The 12 systems change projects across the country are powerful projects linked carefully with our information centers and our clearinghouses, the findings from your projects will be even more powerful if we can get our body of knowledge into practice.

We have goals, tenets, and guiding principles, all of which assume collaboration. As Oliver Wendell Holmes once said, "The great thing in this world is not so much where we stand, as in what direction we are moving." The power of your projects come not only through their direction, but through their findings. It is your findings that contribute a great deal to the direction in which we move.

I have great respect for the work you are doing, and I think we have some exciting times ahead of us. I look forward to progressing together in the directions begun and in meeting the new challenges discussed.

SESSION: General Session No. 3A

Presentation:
Dr. Nancy Safer, Director, DES
"Achieving Important Outcomes"

Thank you for being here this morning. Two years ago I addressed the Project Directors of the Severely Handicapped and Deaf-Blind programs and shared some initial thoughts related to the mission of the DES. It was my sense then, as now, that efforts across programs were directed toward the following goals:

1. Expanding our vision of what is possible in terms of services and outcomes by supporting projects that extend our knowledge base; and

2. Working to make what was possible, probable, by supporting activities that facilitate the adoption and implementation of improved practices.

I invited those attending to share their perceptions as to the appropriate focus for our knowledge and capacity-building activities, and on appropriate strategies to further a substantive agenda. Those attending were generous in their thoughts as were others working in the areas of Early Childhood or Secondary and Transition Programs. Increasingly, it has become apparent, that when issues are framed, and the strategies selected to address them, they must be related to and appropriate to knowledge development or capacity building.

I will share with you today a framework for the DES mission. It is a framework that cuts across the programs in the division. [See Table 1 page 15]

There are six columns. On the far left is column 1, the column of outcomes or overall goals for individuals with disabilities. In column 2 are the implications these outcomes have for education and support services. Column 3 outlines the agenda for service agencies if individuals are to achieve their outcomes. Our primary focus for our activities is at this level, thus, column 3 reflects the outcomes by which we can measure our success. The fourth column indicates our assumptions of what is necessary for effective services. These assumptions have to do with a continuously evolving knowledge base, a system capacity that is expansive and renewing, and collaboration. The previous columns all lead to column 5, the specific goals that cut across DES programs and define the mission of the division. Column 6 outlines the types of strategies used to further each goal.

Two things should be noted: First, the framework does not articulate specific issues or problems to be solved. This is due to the changing nature of strategies. Today, those of you working in research or development projects are hopefully developing the strategies we will be working to get adopted and to see implemented in a few years.

The change over time in our knowledge base was made clear recently when we watched videos of the old Closer Look public service announcements (PSAs). One video, from the early 1970s, was of a young man with disabilities sitting in a group. The announcer said, "Johnny did something today that nobody ever believed he could do." As the young man held up a piece of paper, the announcer continued, "He wrote his name." In 1989 we not only expect Johnny to have written his name but to have written it on an employment form, and go to work.

Clearly, the knowledge base has changed, and with it the problems have become more complex. Thus, we will continue to rely on you and your colleagues in the field, and meetings like this, to assess the emerging issues for knowledge development, as well as the strategies for incorporating this knowledge into standard practice. The strategies are more robust, i.e., less changing in terms of appropriateness. However, they are not perfect. In fact, we ask you to continuously examine the strategies and how they can be better structured.

Last year at this meeting we began to focus on coordination. Specifically, we looked at the range of programs and projects, particularly capacity-building projects, operating in a state, and for ways to mesh them. Our concern was then, as it is today, that the different programs work in a consistent and coherent way. We followed up on that theme during

(continues)

the year by asking, as appropriate, projects to describe in their applications, the relationship between specific project activities and activities listed in State plans under Part B, Section 619, and under Part H. We have been extremely pleased with the coordination reflected in many of the applications, coordination that suggests common objectives related to comprehensive state systems.

I now ask you to focus on a different, but related construct—that of state infrastructures and how they affect our activities and mission. State infrastructure refers to those formal and informal systems and structures that sum to the state's capacity to improve practices and to solve problems. The infrastructure of each state differs; some states rely on institutions of higher education (IHEs), others on intermediate units or cooperatives, still others on professional associations. Many states combine state and federal funds in systematic program improvement activities, while others flow-through almost all Federal dollars to locals for direct services while they themselves rely on ad hoc and serendipitous resources to improve practices. Whatever its structure and support, this infrastructure is important to us for two major reasons.

1. The first reason addresses the evolving nature of the knowledge base referred to earlier. As strategies and models are tested and validated they must be incorporated into a practice base if they are to spread. The projects we fund, including the capacity-building projects, are time and resource-limited. They have neither the duration, nor the resources, to support their implementation until they are widely adopted. Thus, if they do not become incorporated into a more permanent structure of program improvement or renewal, they die out—at least until someone else discovers this gap between knowledge and practice and we begin the cycle again.

A strategy evaluation done for these programs a couple of years ago found that the incorporation of practices beyond the project period was a very real problem. In fact, many practices disappeared from even the original site at the conclusion of the project.

2. The second reason for focusing on the state's infrastructure is due to the role it plays in the state's change process. Whatever its structure within a state, it is the place where people turn for solutions to their problems. This was clarified for us in a recent report on Federal diffusion carried out by the COSMOS corporation. This study looked at districts that had received information or assistance regarding a practice from a Federally-sponsored project and had adopted and implemented the practice. The role the state infrastructure played in disseminating the practices of Federally-sponsored projects was striking. In fact, the linkage of the Federally-sponsored project was often through the state or a state structure (inservice training, staff development workshops, referrals). Also, staff in the targeted local education agencies (LEAs) agreed that they generally turned to their state education agency (SEA), or to their cooperative, when seeking information about practices.

In addition, the follow-up assistance that could be provided by the infrastructure (in addition to any provided by Federal projects) was often key in determining which, among alternative strategies, the LEA selected for adoption. LEAs felt it critical that long-term technical support be available to them when implementing innovative practices.

This seems to have several implications for those of us interested in the state change process.

The first implication concerns the infrastructures within the state where you work. They must be strengthened so that they have the capacity to support practice improvement in ways consistent with our developing knowledge base.

The second implication concerns the importance of the infrastructure in assuring the spread of particular practices. Thus, in working within a state, we must be concerned not only with the implementation of a practice, but also with building the capacity to support others in adopting and implementing the practice. This concept of planned diffusion regrettably has not been a systematic focus of our activities to date.

I end with a challenge to you for the next two days. I, of course, want you to continue to consider how your work fits into some grand scheme of Federal projects. However, my real challenge to you is to discover the structures for change within your state, and to determine how your project links to that infrastructure. Together I hope we can identify ways that we can structure our mutual activities to improve these linkages.

Thank you.

(continues)

Framework For DES Activities

Table 1

TO ACHIEVE

Column 1 **OUTCOMES**	Column 2 **INDIVIDUAL MUST DEVELOP**	Column 3 **SERVICE AGENCIES MUST ASSURE FOR ALL INDIVIDUALS WITH DISABILITIES**	Column 4 **EFFECTIVE SERVICES REQUIRE**	Column 5 **DES GOALS ARE**	Column 6 **USING STRATEGIES SUCH AS**
Living in community Working Making decisions and setting goals Having friends Participating in educational, family, community, and cultural activities Contributing to family and community Self-actualizing	Learning skills Functional living skills and self help skills Vocational skills and work habits Mobility and motor skills Functional academic skills Communication and language skills Social skills Skills in making choices and accessing or advocating for needed supports **Or have access to compensatory systems and services, including:** Family and informal network of friends, neighbors, and general community services providers Formal services and supports Adaptive equipment, services, and environments Equal access to opportunities	Effective, individualized -experiences, education, and other services within normalized, community-based settings to develop requisite skills -support for the family and informal networking and support system so they can provide needed experiences and opportunities -links to formal support services system -assistance and services for modifying environments to make them accessible **As indicated by:** Outcome information as to the status of individuals with disabilities (employment, living situation) Follow-up studies Longitudinal studies Existing data Achievement or child progress data Information about services delivered Number of children identified Monitoring reports LRE data Waiting list data Professional and consumer input	Continuously improving the <u>Knowledge Base</u> of effective programs, procedures, curricula, or technologies that facilitate student attainment of outcomes in community-based settings -development of improved practices for developing particular skills, supports, or accommodations -development of improved practices for particular types of students or families -practices have been tested and are in a usable form -effective practices are adapted and tested for use in integrated community based settings and neighborhood schools <u>Enhancing System Capacity</u> -knowledge of effective models or strategies -support to implement new practices -policies that facilitate delivery of particular services in particular ways -adequate resources • certified personnel • personnel trained to use improved practices • available services, facilities and equipment -receptivity to change -positive attitudes -physical access to services -time available for providing services -needed services are developed <u>Effective Collaboration</u> -Strong family, informal support network developed and actively provides experiences, opportunities, and supports -effective linkages result in full array of services from formal service system overcoming agency barriers and restrictions -public awareness and support for needed services	To increase the effectiveness of services for students with handicaps and their families in settings that enhance the interactions between individuals with disabilities and their peers who are not disabled To enhance the capacity of education and other agencies to provide needed services and experiences To promote collaboration on behalf of students with disabilities	Research projects Research institutes Experimental projects Model development projects Decoder development Comparative features projects, Model evaluation projects, Validation projects Innovative practice projects LRE projects, Institutes Outreach, Utilization projects, Dissemination through regional and State networks, Clearinghouses TA related to policy development, implementation Inservice projects, Personnel training projects, Projects to enhance CSPD, SFA discretionary dollars, Formula grant dollars, Captioned films and TV, Recordings for the blind, Systems change projects Targeted strategy development projects Family networking projects Parent centers and information centers Cooperative models TA related to interagency Community and institution development assistance Public awareness materials, campaigns, TA, NTD

SESSION: General Session No. 3B: ***State-Wide System Change and State and Multi-State Deaf-Blind Projects***

PRESENTERS/TOPICS:

PRESENTATIONS:

Rachel Janney, Virginia Commonwealth University
Terri Rogers-Connolly, Charles Wright, Colorado SEA
Lynn Smithey, Steve Johnson, California SEA
Carla Jackson, Terri Rafalowski, Washington SEA
Chigee Cloninger, University of Vermont
"Putting It All Together—State Coordination of State-Wide Systems Change Projects and State Deaf-Blind Projects"

SESSION CONTENT:

Consideration was given to how, through collaboration between State-Wide Systems Change Projects and State and Multi-State Deaf-Blind Projects, states can effectively plan, implement, and coordinate the provision of educational and related services for their children and youth with severe handicaps, including deaf-blindness. The participating states reviewed their most effective strategies and procedures for implementing best educational practices for this population and identified their next most significant challenges or problems in achieving their goals.

DISCUSSION ABOUT FUTURE DIRECTIONS:

Coordination of State-Wide Systems Change Projects and State and Multi-State Deaf-Blind Projects

Five states presented brief descriptions of the coordination which existed between the state-wide systems change project and the deaf-blind project within the states. Below is a synthesis of the points presented.

FOCUS OF CHANGE EFFORTS:

- The **state-wide systems project** focuses on changing organizations and systems as evidenced from changes in administrative structure, policies, or procedures;
- The **deaf-blind project** focuses on changing people, as evidenced from child change outcomes, teacher change, or local classroom practices change;
- The projects need to focus on the schools, but also on the larger community.

STRATEGIES TO COORDINATE THE TWO PROJECTS:

- Have a clear focus on the mission and values of the projects;
- Identify desired outcomes for each project; the state-wide systems change project focuses on the organizational issues and the deaf-blind project focuses on individual child or classroom change outcomes;
- Interface the structure of the projects with existing structures;
- Share same organizational structure throughout the state, e.g., the same geographic regions;
- Share the same personnel to the extent that it is feasible, including staff and consultants and other state expertise and resources;
- Share local implementation sites;
- Identify a point person at each local site as the one to coordinate local efforts;
- Have joint comprehensive planning efforts with clearly defined role for TA at each local site;
- Address specific needs and build on achievements.

SESSION: Luncheon Speaker

Presentation:
Dr. Robert Davila, Assistant Secretary,
Office of Special Education and Rehabilitative Services

Good afternoon. It is a pleasure to be with you today. I bring greetings from my colleagues in the Office of Special Education and rehabilitative Services (OSERS).

It is an honor to serve as Assistant Secretary of OSERS. I have filled that role for four months now, and during that time, I have learned a great deal. Probably the most important thing I have learned is that, although different disability groups express different needs, there also are many common denominators—common needs—which cut across these various interests. As Assistant Secretary, I am privileged to be in a position to contribute to meeting those needs.

During the first few months of my tenure, I have concentrated on developing a structure within the Office of Special Education and Rehabilitative Services that will enable it to play a vital role in the leadership and direction of services to our constituency. This leadership can be effective, however, only if it complements a collaborative partnership between the public and private sectors. It is my desire to work closely with you and others who possess the knowledge and experience needed to improve the lives of persons with disabilities.

I am a product of special education myself. As a little boy I spoke only Spanish; I knew no English. When I lost my hearing, my mother was faced with the problem of what to do with me. In those days, special education was really special and separate; there were really no options. The child in need of special education went away to school and the parents stayed at home. There were few opportunities for people who were disabled to receive their education in an integrated setting.

My first mainstreaming experience was in graduate school—hardly a place where one would want to begin such an important experience! Although there were some socialization deficits inherent in this system, attending separate schools had the advantage of contributing to academic continuity, and this made for smooth transitions throughout the different phases of my education. One of the joys of my present position is that I have an opportunity to work with people who share my belief in the importance of helping persons with disabilities to make such smooth transitions.

These times are very exciting and hold a lot of promise for persons with disabilities. The Americans with Disabilities Act, for example, will significantly change things for persons with disabilities. Currently, with the exception of public programs supported by Federal funds, it is not unlawful to discriminate against those with disabilities in employment and many other areas of private life, simply because they have a disability. It is hard to believe, but it is true. Soon, however, such discrimination will be against the law and those who are disabled will be given the same protections as their peers who are not disabled.

Having civil rights laws in place, however, does not necessarily assure that things will get better for all people with disabilities. What it does mean is that they will be given **opportunities**, and will not be prevented from achieving what their abilities and interests allow them to achieve. The law will put much more responsibility on all of us, i.e., it will also increase the responsibility of those with disabilities to develop their full potential.

In order to achieve what is needed in this country, a national collaborative effort will be required. Major changes are always difficult, but not impossible. We cannot lose sight of our goals.

I had the privilege of attending the recent education summit held in Charlottesville, Virginia, this past September where the nation's governors committed themselves to the effort to provide better educational opportunities for all students.

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All of the governors brought aides, or advisors, who were primarily their Chief State School Officers. While there, I had the opportunity to sit down and listen to the conversations of these Chief State School Officers. I was hoping to learn some of the problems and concerns their states faced in special education. I heard concerns voiced, but they did not deal with special education exclusively; rather, they dealt with all facets of education.

These conversations confirmed in my own mind what I had already thought—that **the needs of people with disabilities must be viewed and resolved within the context of regular education.** We are special, yes, but we are a part of the educational system as a whole, and I believe that, what is good for all Americans, is good for people with disabilities. We must be guided by that thought as we plan for the future.

Although we have made great progress in providing services to persons with disabilities, we still have a long way to go. The National Council on Disability asked Lou Harris and Associates to conduct a survey—a report card, if you will—on the current state of special education. We need only to read and understand the results to know that we have much more work to do. Five hundred randomly selected individuals participated in this survey. Some of the more disturbing results reported were:

1. 61 percent of parents of children with disabilities know little about their own and their child's rights under key Federal laws that guarantee that service will be provided;

2. 56 percent of all parents still have to struggle to get the education their child needs;

3. 63 percent of parents are dissatisfied with their child's school situation;

4. Only 11 percent of parents and 15 percent of the professionals thought that the schools were doing an excellent job preparing children for life after school.

I entered this job with my eyes wide open. I knew, however, that no one person could do the job alone. I have my own priorities, of course, but to set the agenda for the 1990's requires the help of families, consumers with disabilities, and the professionals who provide the services to them. It also requires collaboration and partnerships, especially among the Federal government, states, local education agencies, and professional organizations. It will only be through your dedication and support that we can do the job we've set out to do.

I am presently in the process of identifying new goals and priorities for OSERS. There are many people in OSERS who are working on this with me, and I am also working closely with many people outside OSERS to seek a consensus on the needs and goals that will guide our performance this year and beyond. We must channel our energies in the direction that is most appropriate. I am most confident that we are on the right road.

Again, I thank you all for your attention. I look forward to working with all of you.

SESSION: Topical Session 1A:

Integrated Education: State of Implementation and Future Directions

PRESENTERS/TOPICS:

PRESENTATIONS:

Anne Smith, OSEP
Introductions and Session Objectives

Wayne Sailor, San Francisco State University
Consensus of What Integration Is—CRI Four Phase Model

Kathryn Haring, California research Institute, SFU
CRI Preliminary Findings

Dotty Kelly, California Research Institute, SFU
CRI Technical Assistance Overview

Diane Ryndak, State University of New York at Buffalo

Bill Sharpton, University of New Orleans
Technical Assistance: State of Implementation

Christine Salisbury, State University of New York at Binghamton

Alison Ford, Syracuse University
Current Innovations

Julia Hightower, University of Utah

Kent Logan, Georgia State University
Do Schools Need to Go through a Period of Evolution When Converting from Segregated Service Delivery to Integrated Service Delivery?

SESSION CONTENT:

The integrated education initiative can be viewed in terms of two philosophical orientations: the first is "values driven"—integrated education is a civil right or an entitlement for all students; the second is "educational outcomes driven"—integrated education is an effective means of achieving desirable outcomes for students. There is no ONE model for providing integrated education. However, factors which promote successful integration efforts include (a) an integration implementation plan complete with desired objectives or outcomes and timelines, (b) site selection and development procedures, (c) general education support and involvement, (d) SEA and LEA administrative commitment, and (e) peer involvement strategies which provide multiple opportunities for social interaction.

DISCUSSION ABOUT FUTURE DIRECTIONS:

Future research efforts should investigate a wide range of issues including:

- Studying the process and impact of State-wide Systems Change efforts within and across states;
- Assessing the benefits of integration for students who do not have disabilities;
- Providing longitudinal follow-up of students who attended integrated and segregated school programs to compare long-term outcomes;
- Providing efficacy data on various integrated and inclusive models and strategies.

Strategies to promote collaborative relationships among general and special education personnel should consist of:

- Preservice training for educators and administrators including practice in integrated settings;
- Cosponsorship of training and service delivery models which are funded by both general and special education.

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Continuing and emerging needs identified include:

- Technical assistance efforts designed to establish integrated educational programs and improve the quality of existing services at state, regional, and district levels;
- Availability of integrated implementation sites across the country which effectively serve pre-school age children and children with complex and challenging needs. Establish and build upon interagency collaboration among IHEs, SEAs, LEAs, MHMR, VR to promote effective educational services for all students.

SESSION: Topical Session 1B: *Transition to Adult Life*

PRESENTERS/TOPICS:

PRESENTATIONS:

Amy Bennett, OSEP
Introductions and Session Objectives
Mike Smull, University of Maryland, School of Medicine
Partnership with the Community
Ian Pumpian, San Diego State University
Transition from School to Adult Life

PANEL:

Kathy Shelby, Childrens' Medical Center, Ohio
Phil Ferguson, University of Oregon
Betsy McGinnity, Perkins School for the Blind
Solving Problems

PRESENTATION:

Adelle Renzaglia, University of Illinois
Applying Industrial Engineering Methods to Vocational Education Practices

GROUP DISCUSSION:

Diane Ferguson, University of Oregon

SESSION CONTENT:

Successful transition from school to adult life is dependent on exemplary secondary school programs and purposeful transition planning which results in young adults with disabilities having a place to live, work and play following school. The session participants described the status of adult services in terms of problems of scarcity of staff, money and available programs and described a necessary theoretical shift from a reliance on adult services to a reliance on the supports that enable individuals to live, work and play in their communities.

DISCUSSION ABOUT FUTURE DIRECTIONS:

- develop a broader transition initiative that not only focuses on work but includes community living and social relationships and expands individual opportunity, access and choice;
- develop or refine strategies that increase collaboration between education and adult service systems;
- describe how the roles of professionals will change if we shift from providing services to orchestrating supports in terms of training, content of work life and relationships with consumers and families.

SESSION: Topical Session 1C:
Communication and Assistive Devices: Reaching Age 22 with Something to Say

PRESENTER/TOPICS:

PRESENTATIONS:

Sara Conlon, OSEP
Introductions and Session Objectives

Victor Baldwin, Teaching Research
A Summary of Activities from the Communications Skills Development Center for Deaf-Blind Children

Kathleen Stremel-Campbell, University of Southern Mississippi
Choices and Options for Learners with Dual Sensory Disabilities

PANEL:

Charity Rowland, Oregon Research Institute
Kathee Christensen, San Diego State University
Barbara Franklin, San Francisco State University
Robert Stillman, University of Texas - Dallas
Harvey Mar, St. Luke's/Roosevelt Hospital Center
Examples of Supported Studies Leading to Better Communication for Children with Severe Disabilities

GROUP DISCUSSION:

Preparation of written report of group recommendations

SESSION CONTENT:

Selected projects were presented which demonstrated diverse approaches to developing communication systems to be used with infants, toddlers, children, and youth with severe communication disabilities and their families.

DISCUSSION ABOUT FUTURE DIRECTIONS:

- study functional communication skills across environmental settings;
- increase linkages between the communication training of children with severe communication disabilities and integration efforts with these children;
- increase interactive forms of communication in social interactions;
- optimize the residual hearing of children with "deaf-blindness" as a first-level interaction with these children;
- enrich the provision by teacher training programs of consistent information that translates research to the practioner level with descriptions of effective instructional methods;
- emphasize student's development of receptive communication skills and behaviors;
- increase the focus on social interactions with peers as the context for interventions;
- design and conduct projects in the context of integrated settings, normal social interactions, and various environments.

SESSION: Topical Session 2D: ***Research and Innovation***

PRESENTERS/TOPICS:

PRESENTATIONS:

Anne Smith, OSEP
Introductions and Session Objectives

Thomas Haring, University of California at Santa Barbara
Units of Analysis of Social Interaction Outcomes in Supported Education

Joni Alberg, Research Triangle Institute
The Center for Educating Students with Handicaps in Regular Education Settings

Richard Young, Utah State University
Training Peer Tutors to Improve the Classroom Behavior of a Student with Severe Handicaps

GROUP DISCUSSION:

Qualitative and Quantitative Methods and Directions for Future Research

SESSION CONTENT:

This session provided an overview of three research and innovative projects which are currently funded by OSEP. The presentations illustrated the broad range of issues and variables which are being investigated in integrated educational programs which promote interactions between children and youth with and without disabilities. Tom Haring presented a three dimensional model within which to examine the characteristics of integrated environments or contexts which facilitate social interactions among students. Joni Alberg described Research Triangle Institute's efforts to identify effective models for educating students with disabilities in general education settings. Richard Young discussed the importance of a functional analysis and use of multiple sources of information to assess and manage challenging behaviors and to promote positive peer interaction among students in a high school setting. The session demonstrated the productive use of a combination of qualitative and quantitative research methods.

DISCUSSION ABOUT FUTURE DIRECTIONS:

Continue supporting research that combines qualitative and quantitative research methods.

SESSION: Topical Session 2E: *Validation*

PRESENTERS/TOPICS:

PRESENTATIONS:

Sara Conlon, OSEP
The Validation Priority

Kathleen Stremel-Campbell, University of Southern Mississippi
Facilitating Adaptations in Family-routine Interactions

Betsy McGinnity, Perkins School for the Blind
Improving and Expanding Social Interaction Skills in Supported Employment Settings

Anne Lamb, Mississippi State University
Validation of Teaching Strategies for Youth with Deaf-Blindness

Barbara Franklin, San Francisco State University
The Effect of Tactile Aids on Communication Skills of Infants and Pre-schoolers with Deaf-Blindness

Thomas C. Clark, Utah State University
Validation of the Intervener Method of Providing Direct Services to Deaf-Blind Children in the Home Setting

Paul Alberto, Georgia State University
A Synthesis of Best Practices in the Education of Students with Profound Handicaps

George Singer, Oregon Research Institute
Home/School Support for Families and Children with Traumatic Brain Injury

James Halle, University of Illinois
Validated Strategies that Facilitate Spontaneous Communication and Extend Pragmatic Functions for Learners with Severe Handicaps

SESSION CONTENT:

There were eight of the 10 validated practices projects presented. Five of these projects were on deaf-blindness, and three on severely handicapped children and youth. The list included validated practices on subjects such as traumatic brain injury, tactile aids on communication skills, validated strategies that facilitate spontaneous communication, and improving and expanding interaction skills in supported employment settings.

DISCUSSION ABOUT FUTURE DIRECTIONS:

An analysis of the eight projects presented, showed five grew out of previously funded projects, one built on a State-funded project, one built on a University research format used for other research projects, and one project was validating intervention procedures. Future Validation Projects have a high possibility of building on other projects funded through the Severely Handicapped Branch, Early Childhood Branch or Division of Innovative Development, OSEP. Dissemination of information concerning validation practices facilitate the replication of ideas from the broad field represented by "severely handicapped" and "deaf-blindness."

SESSION: Topical Session 2F: *Utilizations*

PRESENTER/TOPICS:

PRESENTATIONS:

Patricia Hawkins, OSEP
Introductions and Session Objectives

Barbara Thompson, University of Kansas
Assistive Technology for Students with Severe Disabilities

Deborah Bruskin, ASHA
Technology in the Classroom

Connie Woods, University of Washington
Making an Effective School Program Happen

Jo Ann Somers, Oregon Research Institute
Meeting Needs of Students with Physical Disabilities

Kim McDannel, Northern Illinois University
State of the Art - Illinois Version

Earl Long, King County Human Service
Transition and Individual Future Planning

SESSION CONTENT:

Newly funded projects provided an overview of their project activities. Discussion included results from previous funded programs.

DISCUSSION ABOUT FUTURE DIRECTIONS:

The project briefly discussed utilization as a form of replication. The groups suggested that federal funding be extended beyond the 36 month project period to maximize program outcomes. It was also suggested that federal funding not be competitive for additional project years funding in order to replicate successful project activities.

SESSION: Topical Session 2G: *Personnel Training*

PRESENTERS/TOPICS:

PRESENTATIONS:

Amy Bennett, OSEP
Introductions and Session Objectives

Patty Place, Childrens' Hospital, Akron, Ohio
Inservice Training and Technological Applications

Madeline Appell, St. Lukes/Roosevelt Hospital Center
Field-Based Inservice Training in an Urban Setting

Jan Nisbet and **Cheryl Jorgenson,** University of New Hampshire
Integrating Neighborhood Schools—Training Educational Personnel and Parents

SESSION CONTENT:

This session was designed to highlight preservice and inservice training projects being implemented in a variety of geographical locations and which focused on a variety of training needs.

DISCUSSION ABOUT FUTURE DIRECTIONS:

- Facilitate the coordination of preservice and inservice training instead of using inservice to overcome preservice deficits;
- Continue to explore and refine a team-focused approach to inservice training.

SESSION: Topical Session 2H: ***Demonstration Projects Serving Children and Youth with Deaf-Blindness and Other Severe Handicaps***

PRESENTERS/ TOPICS:

PRESENTATIONS:

Charles Freeman, OSEP
Introductions and Session Objectives

Wayne L. Fox, University of Vermont
Comprehensive Programs for Children and Youth with Deaf-Blindness and Other Severe Handicaps

Kathleen Liberty, University of Washington
Removing Obstacles to Moving Children with Profound Handicaps into Less Restrictive Environments

Ian Pumpian, San Diego State University
Promoting Students' Use of Sensory Input

SESSION CONTENT:

This session reviewed selected projects from the Non-Directed Priority, demonstrating innovative practices for children and youth with deaf-blindness and other severe handicaps. Brief overviews of the three projects facilitated discussion of specific needs for future priority activities and comments focused on the general structure of the grant competitions.

DISCUSSION ABOUT FUTURE DIRECTIONS:

- Barriers to full and equal educational opportunities for persons with severe handicaps include: attitudes; limited human and monetary resources; uneven administrative support; poorly trained teachers; limited information on best practice information; lack of research to support educational activities presently in use.
- Demonstration projects have extended professional knowledge and practice. Local and state educational agencies generally lack the resources to invest in activities for which they do not have mandated responsibility.
- Reinstatement of the "Non-Directed" priority was recommended because of the flexibility it provides applicants to address their specific concerns.
- Dissemination is one of the most critically important areas that requires increased attention. Information about many best practices which have been identified and proven effective needs to be widely disseminated.
- In wording priority statements, limiting the use of the phrase "LRE" is recommended. The words, "inclusion and integration" provide a better description of the desired outcome for children and youth with severe handicaps.

SESSION: General Session No. 4

Presentation:
Patty Guard, Senior Legislative Analyst,
U. S. Department of Education

Good afternoon. I'm really pleased to be here. I would like to compliment the OSEP staff for their success in planning the agenda for this conference. I reviewed it carefully and was struck by how much progress has been made in improving the education, employment and independent living outcomes for persons with disabilities. Yet, as I prepared my remarks, I realized we still have a long way to go.

I would like you to reflect on where we are moving and where we have to go as I describe these bills, particularly the American with Disabilities Act and the medicaid reform legislation, and then to realize the influence your leadership has had in helping to determine the direction we are moving in the area of disability policy.

I have organized my remarks into three parts. In the first part, I will discuss the legislation currently under consideration in the Congress. This includes the reauthorization of the Education of the Handicapped Act Discretionary Programs, the Americans with Disabilities Act, and the Medicaid Reform Bill.

For the second part I will report on the status of the implementation of a bill passed during the last Congress—the Technology Related Assistance for Individuals with Disabilities Act. Finally, I will spend a few moments discussing the outlook for the next session of Congress. There are a number of acts up for reauthorization in 1991 which are important to those concerned with persons with disabilities. There will be a lot of activity concerning the reauthorization of these bills during the next session of Congress.

I will first discuss the reauthorization of the Education of the Handicapped Act (EHA). As you know, Part B of EHA has permanent authorization; thus, we are discussing the reauthorization of the discretionary, or special purpose, programs under Part D. In preparation for the reauthorization, the Senate held one hearing and the House held two hearings.

A number of issues were raised at the hearings that have become themes in the reauthorization. They are as follows:

1. **Changing Demographics of this Nation.** We need to pay attention to minority and culturally diverse populations that are entering special education. We need to improve the services for these populations and to recruit more minority teachers into the profession.

2. **Seriously Emotionally Disturbed Children.** Witnesses have indicated that students who are seriously emotionally disturbed are the most underserved population in special education.

3. **Chronically Ill and Special Health Needs.** We need to provide better services for students with special health needs or who are chronically ill.

4. **Information Dissemination and Utilization.** This topic was a major focus of the hearings and is a major focus in the bills. Congress has been told that information generated through the discretionary projects is not readily available or useable by teachers, administrators and other personnel.

5. **Personnel Preparation in Special Education.** Witnesses stated that the personnel preparation shortage will soon reach a crisis. Therefore, we need to increase manpower planning, recruitment and retention activities.

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At the Senate hearing, and again when he introduced the bill, Senator Harkin, stated that the two previous reauthorizations established major new programs: In 1983 the Early Childhood State Grant Program was established, and in 1986 the new preschool mandate and the infant and toddler program were established. He indicated that this reauthorization would just fine tune the discretionary programs in order not to burden state and local officials who are trying to implement the programs from the previous legislation. He also acknowledged the fiscal constraints under which governments are operating and indicated that we should carefully and deliberately chose our priorities.

Senator Harkin introduced the bill, Senate Bill S. 1824, on October 31st. It was marked up by the Labor and Human Resources Committee on November 1st, [passed Senate by unanimous consent on November 16th]. The major provisions of this bill are:

1. There has been a change in the name. It is now called the "Individuals with Disabilities Education Act of 1989," (IDEA).

2. Throughout the bill, the term "handicapped" is replaced with "children and youth with disabilities."

3. The definitions of handicapping conditions have been expanded. Now included as discrete categories are traumatic brain injury, autism and orthopedically impaired.

Within Section 622: Services for Deaf-Blind Children and Youth are the following changes:

1. Local education agencies are included as eligible applicants.

2. In the area of transition, the phrase "makes transition services available upon reaching the age of 22" is deleted. There would now be no age limitation for people to receive transition services.

3. It includes the authority for early intervention services for infants and toddlers.

4. The authority to fund severely handicapped under this section is deleted.

5. A national center on deaf-blindness is established for the purpose of disseminating materials and information concerning effective practices and other information valuable to those working with persons who are deaf-blind.

Amendments to Section 626: Secondary Education and Transition Services for Handicapped Children and Youth include:

1. A new state grant program in which the Department would make at least five awards, each of which would be for five years. The purpose would be for state education agencies and vocational rehabilitation agencies to submit an application for joint planning around the improvement of transition services for students with disabilities. This is to better prepare a student who goes through this program and leaves special education for entry into the vocational rehabilitation system. Resources will be targeted to school settings to bring vocational rehabilitation counselors into the school to work with individual students, and to provide cooperative links for funding with other agencies besides the school.

2. This section no longer includes just secondary education and transition services. It now includes all the transitions that a young person might go through from the time they enter school until they leave school. Included is an authority for research, demonstration and outreach activities to address the multiple transitions of students in school, such as: 1) from medical care to special education for the chronically health impaired; 2) from residential placements to community based special education programs; and 3) from separate classrooms into regular education classrooms.

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A new section, Section 627: New Programs for Children and Youth with Severe Emotional Disturbance, is added. This includes the authority for research, demonstration and training to improve services to this population. The authority for fiscal year (FY)1990 is two million; it goes to five million in 1991, and increases by one million each year after that. The authority in this section includes studies developing methodologies and curricula, and strategies to reduce the out-of-community placements.

Part D: Personnel Preparation establishes two new priorities in the statute. They are: 1) Recruitment and preparation of individuals from racial, ethnic and linguistically diverse backgrounds and for persons with disabilities for careers in special education, related services, and early intervention; and 2) Preservice preparation of special educators, related service and early intervention personnel to serve individuals with disabilities from diverse racial, ethnic and linguistic backgrounds.

Part E: Research is now titled "Advancing Knowledge and Practice." The language focuses on assessing and improving practice in the provision of special education, related services, and early intervention through the development and exchange of knowledge.

Finally, Section 652 is amended and is now titled Captioned Films, Television, Descriptive Video and Educational Media for Individuals with Disabilities. It authorizes descriptive videos which provide an audio description of video material for visually impaired individuals.

The authorization level in the bill for most of these programs in 1990 is the same as in 1989; there are, however, a few exceptions such as Personnel Preparation. Since we already have appropriation levels established by Congress for 1990, it is more important to look at those years after 1990 where there is about an 8% increase in the authorization levels for most discretionary programs.

On the House side a bill has not yet been introduced. The Democrats and Republicans both have a working draft of a bill which has been circulated among the disability groups for comments. Subcommittee staff are now working on a joint proposal which they hope to have completed by the end of this month.

Within the two bills, many of the provisions are similar to the Senate Bill. Some of the more important features of the House bills are as follow:

1. The title has been changed in both versions to the Individuals with Disabilities Education Act.

2. The Republicans call for reauthorization of the Act every five years; the Democrats have left it at three years;

3. With one exception (the Republican proposal includes $25 million for a new Transition State Grant Program), there are no authorization levels included in either version.

4. The Republican proposal adds new discrete categories for traumatic brain injured, autism, cerebral palsy, attention deficit disorder and serious emotional disturbance or behavior disorder.

5. Both bills contain provisions for addressing the unique problems of minority children with disabilities and their families and the need for minority personnel. The Democratic proposal establishes a major new initiative, which includes:

   a. A 1% set-aside of all funds in Parts B, D, E, F and G to provide outreach and technical assistance for potential applicants who are minority;

   b. A 10% set-aside in personnel preparation for historically or substantially minority institutions; and

   c. A requirement that the highest priority in each program be directed to grant recipients from traditionally or substantially minority institutions, agencies and businesses.

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Section 622: Deaf-blind Programs have the following components:

1. Both parties add local education agencies as eligible applicants;

2. The Republican bill deletes "upon reaching age 22" and changes it to "individuals." The Democrats change the age of 22 to age 18;

3. The Republicans add language that authorizes either a new national clearinghouse or expands the activities of existing clearinghouses to include information about deaf-blind children; and

4. Both bills remove the authority to include severely handicapped under deaf-blind programs.

Section 626: Secondary Education and Transition Services includes a new transition program in the Republican proposal. This program is authorized at $25 million for 1990. It is a significant new program for one time, five year grants to states for planning grants leading to providing all youth with disabilities transition services within five years. The intention is that each state participate. By 1992, each youth receiving transition services would count as 1.5 for the purpose of funding under Part B of EHA. A similar increase, or bonus, is provided for vocational rehabilitation. The latter two provisions are controversial and will probably be omitted from the final House bill. The House Republican proposal is more prescriptive than the Senate version. The Democrat's proposal does not include this program.

Section 627 establishes a new program for Seriously Emotionally Disturbed. The provision, similar to the Senate bill, is included in the Republican bill, but not in the Democrat bill. The Democrats addressed this issue under Part E.

I would now like to talk about the Americans with Disabilities Act (ADA). This is landmark civil rights legislation for persons with disabilities. The provisions for the bill were originally developed by the National Council on Disability. The bill was first introduced in the 100th Congress by Senators Weicker and Harkin. Senate hearings were held. Senators Kennedy and Harkin reintroduced the bill in the 101st Congress with major changes. On the Senate side it was referred to only one committee, the Senate Labor and Human Resources Committee chaired by Senator Edward Kennedy. Hearings were held; negotiations were entered into with the administration; the Committee passed the bill unanimously and S. 933 passed the Senate on September 7th by a vote of 76 to eight.

ADA, as passed by the Senate, would prohibit discrimination against qualified persons with disabilities. Qualified is defined as performing essential functions or meeting essential eligibility requirements whether handicapped or not. Please note the importance of the word qualified. The following provisions are contained in the bill:

1. **Employment.** Employers with at least 25 employees during the first two years of its passage, and with 15 employees thereafter, are required to make reasonable accommodations, unless they can prove that to do so would impose an undue hardship on them;

2. **Public Services.** Mass transportation vehicles and facilities, other than air travel, must become accessible within specified time periods;

3. **Public Accommodations and Services Operated by Private Entities.** ADA requires commercial establishments and private transportation systems, other than air travel, to be accessible—this would include making reasonable modifications, and if not an undue burden, supplying auxiliary aids and services; and

4. **Telecommunications Relay Services.** ADA requires common carriers, within a year, to offer telephone services that provide opportunities for communications that are equal to individuals able to use voice telephone services;

5. **The Definition of the Term Handicapped Has Changed.** The term "handicap" would be defined similarly to the term used in Section 504 of the Rehabilitation Act.

The progress has been slower on the House side. In the House the bill has been referred to a number of committees: the Education and Labor Committee, the Judiciary Committee, the Public Works and Transportation Committee, and the

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Energy and Commerce Committee. The Education and Labor Committee has had the only full committee markup to date; however, the House leadership is intent on passing a bill before the end of this Congressional session. The major issues raised during the hearings include the following:

1. The coverage of any HIV infected person as having a handicap as under Section 504 of the Rehabilitation Act. While all members do not favor the inclusion of HIV infected people, the Administration supports it believing that they need some kind of protection.

2. The coverage of alcoholics and drug abusers is also controversial. The Senate inserted language to say that illegal drug abusers were not included under this and made it clear that employers were not to treat their employees with handicaps differently from those not handicapped concerning drugs and alcohol in the workplace.

3. There are a number of transportation issues.

4. Small businesses have expressed concerns. However, they have been assured that the bill is designed to insure reasonable accommodations.

This is a major priority in the House and it is expected to pass by early next year.

The third major piece of legislation under consideration in the Congress, and of special interest to people concerned with disability issues, is the Medicaid Reform Bill. Currently, Medicaid dollars go to institutions; however, there are state options that provide waivers for states that wish to wave the institution rule and develop a plan to provide cost effective home and community services for eligible persons. Thirty nine states now have such waivers. In spite of these waivers, approximately 87% of Medicaid longterm care funds are directed to large Intermediate Care Facilities for more than 16 persons. Those advocating for Medicaid reform want to see those funds redirected to family support and community based services.

Senator Chafee has been a champion of this effort for some time. The current Senate bill, S. 384, amends Title XIX of the Social Security Act, (the Medicaid program), to assist individuals with severe disabilities in attaining or maintaining their maximum potential for independence and capacity to participate in community and family life. Within five years after the passage of this bill, each state which participated in the Medicaid program would be mandated to provide on a statewide basis a core group of community and family supported services. These services would include individual and family support which includes attendant and respite care, case management, specialized vocational services including supported employment and assistive technology, and protection intervention services. In addition, states could include any one of 20 optional services.

Funding would be limited to community living arrangements with housing provided based on the following formula: No more than three times the average family census in the area; this translates to eight or nine people in most communities. It grandfathers in facilities of 15 or fewer and cluster facilities of up to 24 persons.

The bill would require the states to develop a comprehensive five year plan with an integrated quality assurance system, including standards for each of the services provided. The Secretary of Health and Human Services (HHS) would be prohibited from setting standards, but would be required to monitor the state's compliance with its plan.

On the House side the bill, H.R. 854, has been introduced by Congressman Florio. The House bill is different from the Senate bill in that it offers states the option to offer community based services to Medicaid eligible individuals with mental retardation or a related condition; they do not have to do so and waivers would not be necessary to provide these services. If states chose to provide community based services, states must offer at a minimum:

1. Case management;

2. Respite care; and

3. Personal attendant care.

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The state could also include prevocational, education supported employment and other services. The House bill is silent on the issue of size of new community living arrangements.

The Health Care Financing Administration (HCFA) would develop minimum requirements to protect the health, welfare and safety of clients with respect to providers of community services. Procedures for monitoring and remedies for enforcing compliance with these minimum standards would be established. States would be required to develop their own programs and standards for assuring the quality of these community services.

As for the status of these two bills, the House bill is included in the House Budget Reconciliation package. During the markup of the Senate Budget Reconciliation bill, Senator Chafee reached agreement with Senator Bentsen, Chairman of the Finance Committee that S. 348 would not be offered as part of the Reconciliation package. Thus, when the two budget bills go to conference, it will be in the House bill and not the Senate bill. Action on this issue is likely to continue in the next session.

For the second part of my talk, I will address the status of the Technology Related Assistance for Individuals with Disabilities Act, P.L. 100-407, signed August 19, 1988. Title 1, the only title containing appropriations, assists states to develop and implement consumer-responsive statewide programs of technology related assistance for individuals with disabilities so that they may acquire information about and obtain assistive technology devices and services. Federal dollars, under this program, are intended to function as a catalyst for increasing the availability of and funding for assistive technology devices and services. The governor appointed the agency that would apply in each state for these applications. The statute authorizes up to 10 awards the first year, 20 additional awards in the second year, and the remaining awards in the third year. The final count will depend on the appropriation level since the law requires a minimum and a maximum amount for each award. After three years, if a state can show that it is making progress toward its stated goals, it can apply for two more years of funding, for a total of five years of funding.

During FY 1989, five million dollars were appropriated for this program. The National Institute on Disability and Rehabilitation Research (NIDRR), which administers this program, reported an overwhelming response to this program; 50 applications were received, nine of which were funded for a total of 4.6 million dollars. The states are: Arkansas, Colorado, Illinois, Kentucky, Maine, Maryland, Minnesota, Nebraska, and Utah. Only Nebraska had the state education agency as the applicant agency.

These projects will help coordinate the work of many state and local agencies that help people with disabilities acquire or use assistive devices. The program is designed to avoid duplication and to encourage collaboration among agencies. It also will provide support services, from equipment adaptation to training and financing. The assistive devices may range from simple lapboards for communication to high-technology wheelchairs or computers. A state may buy the equipment or, more likely, suggest ways to finance it.

Title 1 also authorized a contract for technical assistance. $500,000 was awarded to the Rehabilitation Engineering Society of North America (RESNA), of Washington, D.C., to provide technical assistance to the nine states receiving the awards, and to provide information to the states not receiving a Federal technology assistance grant.

In the FY 1990 Appropriations bill, $15 million has been appropriated for this program. While the statute authorizes up to 20 additional awards in 1990, it is expected that there will be approximately 14 additional awards. About two million dollars will be spent for technical assistance, research studies and demonstration activities under Title II. The studies included under Title II are: The National Council on Disability to do a study of the financing of assistive technology devices and services. It authorizes a study of the feasibility of establishing a national information and program referral network in technology related services and assistance, and it authorizes support for training and public awareness through demonstration and innovation projects.

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In looking ahead to the next Congress, we can expect to see a continuation of the Medicaid Reform legislation. The Developmental Disabilities Act expires on September 30, 1990. There will likely be hearings in early Spring with reauthorization to be completed by the end of the fiscal year. In addition, a number of Acts expire on September 30, 1991. They are:

1. **The Vocational Rehabilitation Act.**

2. **The Education of the Deaf Act.**

3. **Part H of the Education of the Handicapped Act (Infants and Toddlers Program).**

4. **The Helen Keller Center Act.**

Hearings will be held on some of the programs during the next session in preparation for the reauthorization.

That concludes my remarks. Thank you for your attention. As the information I have shared with you is subject to change, sometimes overnight, I urge you to keep up-to-date.